

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1368001

Exhibits: WITN1368002-3

Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and I live at **GRO-B**
GRO-B with my husband. I have one
GRO-B

2. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

3. I have Von Willebrand's Disease. I was diagnosed at the same time as my **GRO-B: Sister** but I cannot remember exactly when this was. She had a fall and could not stop the bleeding and as a result the hospital tested each member of our family for Von Willebrand's Disease.

4. I received Factor VIII as a result of my diagnosis with Von Willebrands Disease and I was infected with Hepatitis C as a direct result of being given blood products. **Exhibit WITN1368002** is a letter dated 26th August 2015 to

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- [GRO-B] which confirmed that I was infected with Hepatitis C following receiving blood products for Von Willebrand's Disease.
5. I was under the care of [GRO-B] and I also had treatment at [GRO-B]
 6. I believe that I was infected with Hepatitis C in or around 1977 which was when I attended [GRO-B] for dental treatment.
 7. I recall that in or around 1977 I became particularly poorly. I felt very sick and my skin was yellow and sallow. I remember coming home from work and going straight to [GRO-B] I was initially diagnosed with Yellow Jaunice and was placed in an isolation ward. I had no visitors and was treated horrendously; it was a horrible experience.
 8. No advice has ever been imparted to me in relation to the risk of using Factor VIII. I specifically recall attending for my dental treatment in or around 1977 and can confirm that I received no warning or advice regarding the risks of using Factor VIII.
 9. I think that [GRO-B] was the first consultant to formally advise me that I had contracted Hepatitis C as a result of being given contaminated blood products. I recall that he just mentioned Hepatitis C at the end of one of our normal meetings in the late 1980's. Sometime prior to this [GRO-B] [GRO-B] had mentioned to me that I may have contracted non-A non-B Hepatitis.
 10. [GRO-B] did not give me any advice on how to manage the infection although some time later he did tell me that I could pass it on to others. I was really worried that I had, unwittingly, passed it on to my [GRO-B]
 11. Sometime after my diagnosis of Hepatitis C, [GRO-D] arranged a liver biopsy for me and following this, he telephoned me one Friday evening to advise that I had developed cirrhosis. I do not think that he should have

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given me such dreadful news over the telephone; despite the fact that I had no idea how serious the condition of cirrhosis was at that time. He certainly provided me with insufficient information to enable me to manage the cirrhosis. He advised that I would need a liver scan every three months. I had to carry out my research regarding cirrhosis and when I realised how serious it was I was very shocked.

12. I think that the consultants should have sat me down before the late 1980's and told me about my infection and also provided me with information to assist me in the management of the same. I am not happy with the information provided nor the way in which that sparse information was imparted to me.

Section 3. Other Infections.

13. I recall receiving a letter confirming that I had been put at risk of vCJD.

Section 4. Consent.

14. I was never told that I was being tested for firstly non-A, non-B Hepatitis nor was I advised later on that I was being tested for what they now knew non-A, non-B Hepatitis to be, which was Hepatitis C. I was therefore tested without my knowledge and therefore it follows that I was tested without my consent.

15. I was also tested for HIV and this was without my knowledge and therefore without my consent.

16. I believe that I have also been tested and treated for the purpose of research. I recall signing some paperwork following confirmation that I had contracted Hepatitis C. I did not receive much information or advice but I think that I was used for the purpose of research which they asked me to take part in.

Section 5. Impact

17. It is frightening having cirrhosis and I ponder each day what my future holds. Recently a lot of things have been going wrong for me health wise and I wonder if this is now the end.

18. In addition to cirrhosis I also have a mitral valve prolapse, an under active thyroid and osteoarthritis. The osteoarthritis means that my mobility has been severely affected and I struggle to get upstairs or to walk any distance. **Exhibit WITN1368003** is a letter dated 21st February 2018 to **GRO-B** from **GRO-B** which confirms both my liver and non-liver diagnoses.

19. I have to take a great deal of medication and this includes Hepa—Merz 3g Granulat for my liver. This medication stops the liver toxins entering my brain. This is a very expensive medication which has been sourced from abroad and the medical professionals are constantly trying, no doubt due to financial pressures, to cease prescribing this medication.

20. I believed the consultants when they said that I had Yellow Jaundice. I never thought that I had anything else. However, I never felt right and was constantly faint, utterly exhausted and then became extremely anaemic.

21. I underwent Interferon and Ribavirin treatment for my Hepatitis C but I cannot remember when this was. Unfortunately I had to discontinue the treatment part way through due to the fact that it made me so poorly. Following this treatment, **GRO-B** then prescribed me Interferon and Amantadine which is usually prescribed for people who have been diagnosed with Parkinson's Disease. I had to go to St Mary's Hospital in Paddington who advised me which treatment I would now be put on. However, they told me that I had to go to St Mary's Hospital at Roehampton to obtain the treatment due to funding issues.

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22. I was initially advised that I had cleared Hepatitis C following the treatment but then I was told that this was not the case. I therefore do not know if I still have Hepatitis C.
23. The treatment was truly horrific; I felt like I had severe flu twenty-four hours per day. My memory has also been badly affected.
24. I struggled mentally during and following the treatment for Hepatitis C. I used to work GRO-B but even this was a real struggle.
25. The consultants have refused to carry out my impending knee replacement and instead they have put rods in my knee to burn off the nerves and this has helped a little but I do need the knee replacement. I am not sure why I have been refused this operation.
26. Being diagnosed with Hepatitis C has seriously impacted upon how consultants treat me. Whenever I was admitted to hospital, the medical staff dressed up like space men whenever they approached me. It was deeply hurtful.
27. I was never able to obtain a normal dentist. I was always told that it would be unsafe for them to treat me. I used to be under the care of GRO-B and she was not bothered by my infected status. Unfortunately she has now retired and I do not know if any new dentists will take me on.
28. Hepatitis C has had an impact on my family life. I told my family in the late 1980's but they did not want to know. Sometimes I would go and visit my family and they would not let me drink out of their cups. This also happened when I used to visit "so called friend's" houses. It was soul destroying.
29. My s also contracted Hepatitis C from contaminated blood products. I believe that we were infected at around the same time which was when we both went for dental treatment in or around 1977. Unfortunately my sister has now passed away which is terribly sad.

30. I have suffered stigma at work due to my Hepatitis C infection. When I used to work as a classroom assistant, the head teacher and other teachers advised that I must not tell ANYONE about my infection.

31. Financially I have struggled. Due to the fact that I was too poorly to hold down a regular job with regular hours, the consequence was that my **GRO-B** had to work both days and nights. This put a strain on our relationship but we are still together today as we are as strong as ever.

Section 6. Treatment/Care/Support

32. In September 2018 I went to **GRO-B** for an endoscopy but they really struggled with the tube so they decided that I required a capsule endoscopy. I recall that the hospital sent a letter to my GP advising that they were not going to fund this. It was a really difficult time and I had to fight to have treatment. I thought that the NHS had given me Hepatitis C so they should at least be prepared to fund any treatment or associated costs.

33. I did not get offered counselling straight away and I believe that I should have been offered this more promptly. However, I was eventually offered counselling but I think the time had passed and it was of no benefit to me.

Section 7. Financial Assistance

34. I found out about The Skipton Trust from the Daily Express in or around the late 1980's.

35. I received the Skipton Stage 1 lump sum payment of £20,000.00 and the Skipton Stage 2 lump sum payment of £25,000.00. I also receive monthly payments from The Skipton Trust and these were recently raised to £1,700.00 per month. In November 2012 I received a £500 winter payment for fuel costs from The Skipton Trust.

36. The process of applying was reasonable; I had to fill in a form and prove to them that I had cirrhosis. The Haemophilia Centre in GRO-B managed and oversaw the application procedure.

37. I was not aware that you could apply for any grants because The Skipton Trust did not send out regular information. Therefore, I have not applied for any grants.

38. I believe that The Skipton Trust was not fit for purpose because some people who knew how to work the system obtained grants totalling several thousand pounds whereas others like me were not even aware grants existed.

Conclusion

39. I want to know why people become medical professionals if they were going to cause damage to their patients. The medical professionals gave their patients contaminated blood products whilst knowing that we were going to be infected with viruses. I am still very upset and angry with regard to the situation and I want answers for my s and I.

40. Compensation is not going to make everything better, but it could make victims lives easier. I had to fund my own wheelchair to assist with my poor mobility; this being a direct result of my infection with Hepatitis C.

Anonymity, disclosure and redaction

41. I wish to remain anonymous and I do not want to give oral evidence to the Inquiry.

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Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed.....

GRO-B

Dated... 11. 12. 18